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Nos. 79-1404, 79-1408, 79-1414, 79-1415 and 79-1489

IN THE

Supreme Court of the United States

OCTOBER TERM, 1980

PENNHURST STATE SCHOOL AND HOSPITAL, *et al.*,
Petitioners

v.

TERRI LEE HALDERMAN, *et al.*,
Respondents

On Petition for a Writ of Certiorari to the United States Court of Appeals for the Third Circuit

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BRIEF OF THE AMERICAN BAR ASSOCIATION AMICUS CURIAE

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QUESTIONS PRESENTED BY AMICUS

1. Whether mentally retarded persons have a privately enforceable right to receive appropriate treatment, services, and habilitation in a setting that is least restrictive of personal liberty when in the custody of a state receiving federal funds under the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §§ 6000 *et seq.*

2. Whether 42 U.S.C. § 1983 provides a remedy to enforce the provisions of the Developmentally Disabled Assistance and Bill of of Rights Act, 42 U.S.C. §§ 6000 *et seq.*

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BRIEF OF THE AMERICAN BAR ASSOCIATION AMICUS CURIAE

INTEREST OF AMICUS CURIAE

The American Bar Association is a national membership organization of the legal profession. It counts as members more than 260,000 lawyers from all states and the District of Columbia and has, since 1944, maintained an active interest in the field of mental disability law.[1]

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[1] The Association established a Special Committee on the Rights of the Mentally Ill 36 years ago; this committee's recommendations

This interest was expanded in 1973 when the Board of Governors of the American Bar Association established a Commission on the Mentally Disabled, a 17-member interdisciplinary body charged with promoting effective legal assistance to the mentally disabled and with recommending and implementing programs designed to correct pervasive deficiencies in the nation's mental disability system.

Since its inception, the Commission on the Mentally Disabled has focused its efforts toward, *inter alia*: mobilizing, activating, and awarding grants to local and state bar associations to encourage legal representation of the mentally disabled (including appropriate substantive technical assistance); establishing and publishing the *Mental Disability Law Reporter*, an interdisciplinary journal which reports significant developments in the mental disability law field; operating a resource center to aid legal research; and developing model legislation to assist states in revising and updating their statutes dealing with the mentally retarded and other developmentally disabled persons.

The Commission on the Mentally Disabled has been active in shaping Association policy with respect to the mentally disabled. Pursuant to a Commission recommendation, the Association's House of Delegates adopted in August, 1978, a policy statement calling for, among other things, enforcement of "existing laws and regulations which prohibit discrimination against mentally disabled persons . . . ," and state protection of "a right of treatment/right to habilitation" and of "a right to treatment in the least restrictive setting" (see Appendix A).

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led ultimately to the publication of a number of path-breaking studies by the American Bar Foundation, created by the Association in 1952. *See* Lindman & McIntyre, *The Mentally Disabled and the Law* (1961); Rock, Jacobson, & Janopaul, *Hospitalization and Discharge of the Mentally Ill* (1968); Matthews, *Mental Disability and the Criminal Law* (1970); Brakel & Rock, *The Mentally Disabled and the Law* (rev. ed. 1971).

The House of Delegates also adopted a resolution sponsored by the Commission on the Mentally Disabled in August, 1977, which "urges the swift and effective implementation of federal laws and regulations codifying the rights of mentally handicapped persons. . . ." (see Appendix B). Thus, the Association has special experience and particular interest in the question now before the Court.

With due consideration of the extended factual and legal analysis offered in the briefs of the parties and other *amici*, the Association, with the written consent of the parties,[2] sets forth its views herein on the important question of whether mentally retarded persons have a judicially enforceable statutory right to habilitation in the least restrictive setting.

STATEMENT OF THE CASE

On May 30, 1974, a class action lawsuit was filed in the United States District Court for the Eastern District of Pennsylvania by Terri Lee Halderman and other mentally retarded residents of Pennhurst State School and Hospital alleging that they were subject to chronic abuse and neglect (resulting in intellectual and physical regression), lack of supervision, inhumane and dangerous conditions, and nonexistent opportunities for appropriate community care. See 15a, 94a-95b. Violations of constitutional as well as federal and state rights were alleged.

The Parents and Family Association of Pennhurst was added as plaintiff on July 29, 1974. The United States was granted leave to intervene as plaintiff on January 17, 1975, and the Pennsylvania Association for Retarded Citizens was similarly granted leave to intervene

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[2] Copies of letters indicating the parties' consent have been filed with the Clerk of the Court.

on November 12, 1975. The certified plaintiff class consists of all persons "who . . . have been or may become residents of Pennhurst." 14a, 96a.

After a thirty-two day trial, the District Court ruled that the conditions at Pennhurst were so inadequate and debilitating that plaintiffs had been denied their rights under the Due Process Clause, the Equal Protection Clause, Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. § 794), and the Pennsylvania Mental Health and Mental Retardation Act (Pa. Stat. Ann. tit. 50, § 4201 *et seq.* (Purdon 1969)). Despite three opportunities, defendants failed to submit a plan for the implementation of these rights, and on March 17, 1978, the trial court entered its judgment for plaintiffs, ordering interim steps for the improvement of conditions at Pennhurst and the development of plans for the closing of Pennhurst itself and the removal of its residents to more appropriate, less restrictive community living arrangements.

Defendants filed appeals to the Court of Appeals for the Third Circuit and on December 13, 1979, that court affirmed the District Court's findings of liability. Specifically, the *en banc* Court of Appeals held that defendants' actions violated both the Developmentally Disabled Assistance and Bill of Rights Act (42 U.S.C. §§ 6001-6081) and Pennsylvania statutes (Pa. Stat. Ann. tit. 50, §§ 4201 *et seq.* (Purdon 1969)). The court condemned the "abominable" conditions at Pennhurst (103a), with the dissenting judges acknowledging those "deplorable conditions" (162a). Because of Pennhurst's shortcomings and the fact that many of its residents could immediately be moved into the community, the Court of Appeals held that the Commonwealth must determine on a case-by-case basis which individuals could be appropriately cared for at an improved Pennhurst, and which should be placed in the community. 157a.

The Court of Appeals avoided the constitutional issues addressed by the District Court by finding an enforceable right to habilitation under federal law. The court also relied on state statutes and case law to find a right to habilitation.

SUMMARY OF ARGUMENT

Developmentally disabled persons were granted a number of important new rights by Congress when it enacted the Developmentally Disabled Assistance and Bill of Rights Act in 1975. Paramount among these are the right to appropriate treatment, services, and habilitation, and the right to receive such treatment in the least restrictive setting—all of which were enacted in conjunction with a national policy change embracing deinstitutionalization. These rights vest personally in the developmentally disabled, unlike other rights created by the statute which operate only as conditions of fiscal performance under the Act.

A close reading of the language of the pertinent provisions of the Act, an examination of its overall structure, and a thorough review of its legislative history reveal the fundamental nature of these rights. The Commonwealth of Pennsylvania bound itself to the observance of these rights upon agreeing to participate in the Act's programs. This would be true whether one concludes Congress acted to implement the Fourteenth Amendment pursuant to Section 5 or to provide for the general welfare pursuant to Article I, Section 8.

This Court has recently ruled that in the case of the Social Security Act, federal statutory rights may be enforced by way of private right of action under 42 U.S.C. § 1983. The Developmentally Disabled Assistance and Bill of Rights Act establishes rights even more worthy of enforcement under § 1983.

ARGUMENT

I. The United States Congress Granted Mentally Retarded Persons the Right to Appropriate Treatment and Habilitation in the Least Restrictive Setting Under the Developmentally Disabled Assistance and Bill of Rights Act.

The numerous deficiencies of Pennhurst are not substantially different in kind or magnitude from those found at other large institutions throughout the country. The horrid results produced by our institutions are part of a system which has tried to deliver vital services to developmentally disabled people in isolated, dehumanizing settings which encourage personal abuses.[3] The severity of the problems is precisely why Congress felt so compelled to act to protect the interests of institutionalized developmentally disabled persons on a national scale.

This Court itself has recognized the destructive power of isolation and has unquestionably stimulated congressional investigations of civil institutions. *O'Connor* v. *Donaldson*, 422 U.S. 563 (1975), put an end, at least as a legal practice, to institutional warehousing of nondangerous individuals who could live in less restrictive surroundings with the assistance of friends, relatives and the community. A similar principle was upheld recently in *Parham* v. *J.L.*, 442 U.S. 584 (1979), a case which recognized the need to constitutionally guarantee that mentally retarded children, like their adult counterparts, are "free of unnecessary bodily restraints" (*Id.* at 601) and are "not being labeled erroneously" (*Id.* at 601), two familiar practices in institutional settings.

Congress chose to address these problems for developmentally disabled people not with a "neutral factfinder," which is the minimal constitutional protection necessary

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[3] *See, e.g.*, Rothman, David J. *The Reform of the Asylum: Between Conscience and Convenience in Progressive America* (1980).

for children (*Id.* at 606), but with a bill of rights which includes individual legal redress when those rights are violated. Moreover, because of the intensity of past abuses, Congress prefaced those rights with a rebuttable presumption that deinstitutionalization is preferred.

The rights of mentally retarded and developmentally disabled people[4] have been the focus of congressional concern for a number of years. As early as 1963, Congress saw fit to enact funding legislation aimed at protecting such rights by the creation in the states of facilities and services that would adequately meet the needs of these people. Mental Retardation Facilities and Community Mental Health Centers Construction Act, *P.L. 88-164*, 77 Stat. 282, 88th Cong. (1963). This approach was furthered by congressional refinements adopted in 1967 and 1969. Mental Retardation Amendments of 1967, *P.L. 90-170*, 81 Stat. 527, 90th Cong. (1967), extended by the Developmental Disabilities Services and Facilities Construction Act, *P.L. 91-517*, 84 Stat. 1316, 90th Cong., 1st Sess. (1969).

Congress redirected its concern for the proper care and training of the developmentally disabled in 1975 by enacting the Developmentally Disabled Assistance and Bill of Rights Act (hereinafter "the Act"), 42 U.S.C. §§ 6000 *et seq.* The Act changed the previous patterns of federal funding by adding the Bill of Rights provision at issue in this case, 42 U.S.C. § 6010, and thereby fundamentally altered the manner in which federal and state units of government would serve the mentally retarded.

This evolution in congressional approach, from the straightforward provision of funds for facility construction to the emphasis on mandatory rights set forth in the

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[4] The term "developmental disability" is defined at 42 U.S.C. § 6001(7) and includes such conditions as mental retardation, cerebral palsy, epilepsy, autism, and learning disabilities.

federal statute, itself suggests the magnitude and persistence of the nation's failure to humanely care for its developmentally disabled citizens.[5] And it is this failure that motivated the drafters of the Act to establish certain rights and guided them in their specific formulation.[6]

A. *These Rights are Clearly Set Forth in the Language and Structure of the Act Itself.*

At the outset, it should be noted that the very name of the Act, the "Developmentally Disabled Assistance and *Bill of Rights Act*" (emphasis added), reflects the extent to which Congress was moving beyond a limited funding statute. Every state considering participating in the program set up under the Act was surely on notice that part of the bargain would be mandatory protection of a certain number of "rights" considered important by Congress.

The actual Bill of Rights provision of the Act, 42 U.S.C. § 6010, expressly applies to "persons with developmental disabilities"; no additional limitations are set forth. The Act declares that such persons:

> have a right to appropriate treatment, services, and habilitation for such disabilities. [§ 6010(1).]

It goes on to define and specify the content of that right in the very next subsection:

> The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty. [§ 6010(2).]

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[5] 42 U.S.C. §§ 6001 *et seq.*, P.L. 94-103, 89 Stat. 502, 94th Cong., 2d Sess. (1975), amended, P.L. 95-602, 92 Stat. 2955, 95th Cong. (1978). See S. Rep. 94-160, 94th Cong., 1st Sess. 28-34.

[6] S. Rep. 94-160, 94th Cong., 1st Sess. 28-34 (1975).

Thus, at the beginning of the Act's Bill of Rights stands the clearly stated principle that mentally retarded persons are entitled to appropriate treatment [7] with minimum encroachment upon personal liberty.[8] Read together, subsections (1) and (2) represent an unequivocal statement by Congress of the overall spirit of this statute and of the most basic rights owed to developmentally disabled persons.

Congress' intent is further clarified by subsection (3), which proceeds to define how public funds are *not* to be used insofar as the developmentally disabled are concerned. The obligation of both the federal and state governments is "to assure that public funds are not provided to any institutional or other residential program for persons with developmental disabilities that (A) does not provide treatment, services, and habilitation which is appropriate to the needs of such persons. . . . § 6010(3).[9]

Congress obviously decided it was necessary to repeat the requirement for "treatment, services, and habilitation" in the context of governmental duties arising out of the use of "public funds," even though this already had been stated in the immediately preceding subsections.

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[7] The Act, reflecting accepted practice in the developmental disability field, distinguishes between treatment, which applies to curable mental illness, and habilitation, which consists of education and training for those, such as the mentally retarded, who are in no sense ill. The legal right is identical for each, and for that reason the terms are used interchangeably herein.

[8] The Association's House of Delegates has adopted a policy specifically endorsing both the right to treatment in the least restrictive setting. (For the full text of this policy, see Appendix A to this brief).

[9] Subsection (B) sets forth six minimum standards for institutional or residential programs, covering diet, medical care, use of physical restraints, use of chemical constraints, visitation, and fire and safety. 42 U.S.C. § 6010(3)(B).

The mildest deference to the plain language used in these lines forces one to acknowledge that subsections (1) and (2) establish rights inherent in the developmentally disabled person, while subsection (3) creates rights available only where government funds have become directly involved.[10] The Court of Appeals, in reviewing these subsections, observed:

> It is hard to see how Congress could have been any more precise in revealing its intention to confer a right to treatment or habilitation. 612 F.2d 84, at 96.

But Congress did endeavor to be more precise in 1978, when it supplemented the Bill of Rights with the following:

> The rights of persons with developmental disabilities described in findings made in this section are in addition to any constitutional or other rights otherwise afforded to all persons. [*P.L. 95-602*, Title V, § 507, 92 Stat. 3007 (Nov. 6, 1978).]

Only by the gross distortion of ordinary English could this provision be read to suggest anything but that Congress was intentionally establishing new rights in § 6010. By adding this sentence, Congress eliminates any doubt that subsection (1) and (2) rights are in fact personal rights of the developmentally disabled themselves.

The dichotomy of § 6010, with its creation of basic personal rights separate from conditions running only with the flow of public funds, is also present in the Act generally. For instance, Subchapter III of the Act, 42

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[10] *See* H. Conf. Rep. 94-473 at 42, reprinted at [1975] U.S. Code Cong. & Ad. News 943, 961. Under the approach taken by Congress, any facility failing to provide a "nourishing, well-balanced daily diet," as required by § 6010(3)(B)(i), for instance, would face loss of public funds. However, residents of that facility would still retain those rights set forth in § 6010(1) and (2).

U.S.C. §§ 6061-6068, creates a program for the distribution of federal funds to states for developmental disability services. Each section contains detailed and specific requirements and mechanisms by which allotments to states for planning, construction, administration, and services are to be made. Clearly, the Congress is not hesitant or obscure when it intends specifically to condition the use of its money under the Act. Such unmistakable conditions are glaringly absent from subsections (1) and (2) of § 6010.

The heart of the funding portion of the Act, however, concerns the preparation and submission of state plans. Any state wishing to participate under Subchapter III must submit a plan for the provision of services and facilities for persons with developmental disabilities to the Secretary of HEW [11] which must address numerous "conditions for approval." 42 U.S.C. § 6063(b). Furthermore, each state must create a state planning council of specified composition which, among other things, must "supervise the development of and approve the State plan . . ." 42 U.S.C. § 6067(b)(1). Where federal funds are concerned, the Act is replete with specific conditions and restrictions placed on the states by Congress.

Elsewhere in the Act, Congress has required that as a condition to receiving an allotment, states must have an individual habilitation plan for each developmentally disabled person served thereunder. 42 U.S.C. § 6011(a). Again, Congress demonstrated its capability of linking conditions to use of its funds when it so desired. The Bill of Rights found in the preceding section of the Act, § 6010, particularly subsections (1) and (2), contains no such restriction.

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[11] The Department of Health and Human Services is the successor agency to the Department of Health, Education and Welfare. 20 U.S.C. § 3508.

Finally, the Act's program for "protection and advocacy of individual rights" affirms the distinction the Act maintains between enforcement and funding provisions. 42 U.S.C. § 6012. Itself a condition to the receipt by a state of its allotment under the Act, the program is independently funded and invested with the authority to "pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation . . ." 42 U.S.C. § 6012(a)(2)(A). This authority taken with the section's requirement that the program be "independent," unmistakably indicates that Congress did not intend merely to police state compliance with spending conditions, but to ensure that actual legal rights were enforced.

B. *The Legislative History of the Act Reveals Congress' Intent to Establish These Rights.*

The policy shift which supports deinstitutionalization is not an isolated preference by Congress limited to developmentally disabled individuals or the Developmental Disabilities Act. Several other important federal programs demonstrate the existence of a national deinstitutionalization movement during the 1970s.

According to a government report,[12] Title XIX of the Social Security Act (Medicaid), 42 U.S.C. §§ 1396, *et seq.*, is "one of the most important factors affecting deinstitutionalization." In recent years the thrust has been to establish community alternatives such as the intermediate care facilities for the mentally retarded (ICF/MR).

Under Title XX of the Social Security Act, 42 U.S.C. §§ 1397 *et seq.*, Congress has stated that one of its major

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[12] Government Accounting Office Report to Congress: Returning the Mentally Disabled to the Community, HRD-76-152A (Jan. 7, 1977).

goals was "preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care." The implementing regulations, which are based in large measure upon the legislative history, prescribe that Title XX funds "only be used to encourage the development of safe and appropriate residential settings as an alternative to institutional living for appropriate elderly individuals and handicapped children and adults. . . ." 43 Fed. Reg. 4016 (1978).

Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, while encompassing all kinds of discrimination against the handicapped, evidences a particular concern in its legislative history against segregation of handicapped individuals into isolated institutions. [1978] U.S. Code Cong. & Ad. News 7312.

Finally, the Community Mental Health Centers Act, 42 U.S.C. §§ 2689 *et seq.*, was enacted to establish community mental health centers as alternatives to isolated state institutions.

It is in this context that the Developmental Disabilities Act was proposed, and it is in this context that it should be read.

The fundamental focus of the Developmentally Disabled Assistance and Bill of Rights Act, if not obvious after a close reading of its many provisions, is revealed clearly in the legislative history.

Senator Harrison Williams, in supporting the House-passed version of the proposed Act (introduced in the Senate as S. 462), observed:

> While much can be said about the lack of available funds to improve conditions at these institutions, at some point this country must draw the line. The abuses are too commonplace to point at a single in-

> stitution, or a single abuse and say that it is an anomaly. [121 Cong. Rec. at 16516-17 (1975).]

The Senate Committee stated its understanding as follows:

> The Committee is firmly convinced that Congress must take action to ensure the humane care, treatment, habilitation and protection of the mentally retarded. The Federal Government has the responsibility to provide equal protection under the law to all citizens. [S. Rep. 94-160 at 32 (1975).]

Senator Jacob Javits described the public responsibility more bluntly:

> Congress should provide the leadership to change the tragic warehousing of human beings that has been the product of insensitive Federal support of facilities providing inhumane care and treatment of the mentally retarded. [121 Cong. Rec. at 16519.]

The virulence of this scandal was not easily checked, and during consideration of amendments to the Act in 1978, Senator Edward Kennedy felt compelled to observe:

> Mr. President, this is a program which I think is strongly needed. I do not know how many times we have had television documentaries on Willowbrook, and Forest Haven, and other institutions in this Nation, and still nothing gets done. [124 Cong. Rec. S15663 (daily ed. September 21, 1978).]

The approach chosen by the Congress was not merely to throw more money at the problem, but to end the discrimination as a matter of law. The remedy was to establish clear and definite rights, 42 U.S.C. § 6010, and to provide a mechanism for their enforcement, 42 U.S.C. § 6012. The rights established were meant to be commensurate with the seriousness of the inequity:

> These rights are generally included in the conference substitute in recognition by the conferees that the

> developmentally disabled, particularly those who have the misfortune to require institutionalization, have a right to receive appropriate treatment for the conditions for which they are institutionalized, and that this right should be protected and assured by the Congress and the courts, H.R. Conf. Rep. 94-473, 42 (1975), [1975] U.S. Code Cong. & Ad. News 961.

The Bill of Rights referred to by the Conference Report was the result of a substantial amount of congressional drafting and review. The Senate emphasized the need for institutional standards:

> Testimony before the committee demonstrated that standards in institutions for the developmentally disabled are urgently needed and that the Federal Government should play a major role in improving the care and services provided to developmentally disabled citizens. [Remarks of Senator Schweiker, 121 Cong. Rec. 16521 (1975).]

The Conference Committee report leaves no doubt that concrete rights were being established in Title II:

> The Conference substitute contains a compromise which enumerates Congressional findings respecting the rights of persons with developmental disabilities. These include findings that the developmentally disabled have a right to appropriate treatment, services and habilitation; that such treatment, services and habilitation should be designed to maximize the developmental potential of the person and be provided in the setting that is least restrictive to his personal liberty. . . . [H.R. Conf. Rep. No. 94-473, 41-42 (1975), [1975] U.S. Code Cong. & Ad. News 961.]

Senator Tom Stafford pointed out that "Title II was added to the bill to assist in the protection of the rights guaranteed under our Constitution for those individuals that will require institutionalization. . . ." 121 Cong. Rec. 16516 (1975). In Senator Schweiker's view, the Bill of Rights was needed to require "[h]umane care, treatment,

rehabilitation, and protection in residential facilities. . . ." *Id.* at 16522.

Having defined the need for federal action in the area of personal rights, Congress placed the "right to appropriate treatment, services, and habilitation for such disabilities" as the first priority. 42 U.S.C. § 6010(1). And, having eschewed enacting a detailed blueprint for the operation of institutions (Conference Report, *supra* at 41-42) Congress went to the simple and obvious alternative—a general right to "appropriate treatment." Senator Allan Cranston noted that the bill

> recognize[d] that the need for some long-term residential programs will remain. The bill specifically provides that where institutional programs are appropriate, adequate support should be planned for them so that necessary treatment and habilitation programs can be given residential patients to develop their full potential. 121 Cong. Rec. 16520 (1975).

Senator Williams, recalling committee testimony of such institutional abuses as "inappropriate and inhuman experimentation with residents, sterilizations and other operations performed for convenience of treatment, starvation and malnutrition, abuse and physical punishment, inadequate food and living conditions, and death," *Id.* at 16517, concluded that

> S. 462 provides a framework by which the constitutional rights of residents and other persons with developmental disabilities may be enforced. *Id.*

Clearly, the Act was conceived and enacted as a multifaceted device through which the scandal of the institutions was to be addressed. The "right to appropriate treatment" simply spells out the unifying theme that the failure to provide adequate treatment and care for the developmentally disabled can be tolerated no longer. Even the lengthy dissenting opinion of the Court of Appeals

declines to challenge this right to treatment or its enforceability, 612 F.2d at 117.

Congress accurately perceived, however, that the scandal was not limited to the way people were treated in the institutions. As unforgivable as the conditions in institutions were, there was a greater injustice:

> It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in these institutions at all. Efforts to assure proper treatment, education, and habilitation services in large institutions should not deflect attention from the fact that most of these institutions themselves are anachronisms, and that rapid steps should be taken to phase them out. S. Rep. 94-160 at 32-33.

And Congress realized that deinstitutionalization was an essential ingredient to appropriate treatment:

> Many of these institutions by their very nature, their size, their isolation, their impersonality, are unsuitable for treatment, education, and habilitation programs. *Id.* at 33.

Representative Andrew Young, when moving the bill out of the House Rules Committee, stated:

> Of particular significance in this bill is the emphasis on deinstitutionalization which would discontinue institutional maintenance and develop adequate community programs to serve this population. 121 Cong. Rec. at 9965 (1975).

Senator Cranston expressed his understanding of the purpose of the Act as follows:

> I believe one very clear basic goal has been enunciated in the legislation reported from committee. That is the need to move away from long-term institutionalization of individuals with developmental disabilities to the development of community-based pro-

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BRIEF FOR CONGRESS OF ADVOCATES FOR THE RETARDED, INC., et al., AMICI CURIAE

INTEREST OF THE AMICI

As more fully explained in the motion for leave to file this brief (hereinafter "Motion"), *amici* are organizations of parents, relatives and other advocates of the interests of retarded people who believe that the decision below, by establishing a presumption in favor of the court-ordered removal of retarded individuals from institutions, will produce results contrary both to Congress' intent and to the best interests of the retarded. *Amici* therefore support the position of those petitioners who contend that this presumption should be set aside.

INTRODUCTION AND SUMMARY OF ARGUMENT

The court below has held that § 6010(2) of the Developmentally Disabled Assistance and Bill of Rights Act (hereinafter "the Act") empowers the federal courts to relocate retarded persons to the "least restrictive environment" in which they can be treated. 612 F.2d at 103-107. And, the court has further held that in exercising that power, "the court or the Master should engage a presumption in favor of placing individuals in CLAs [community living arrangements]" rather than in institutions, with institutionalization permitted only in an "extreme situation." Id. at 115-116. As explained in the Motion, p. iii, in many cases retarded persons, their parents and their professional advisors do not favor transfers from institutions to CLAs—i.e., nursing homes, foster homes, "board and care" facilities, or private homes or apartments whose proprietors have contracted with the state to supervise one or more retarded persons.[1] But the ruling below would result in such transfers nonetheless.

[1] For discussions of the types of CLAs, see R. Bruininks, F. Hauber and M. Kudla, National Survey of Community Residential Facilities 11-12, 56, 60 (Developmental Disabilities Project on Residential Services and Community Adjustment, University of

In this brief, *amici* do not address the threshold question whether the statutory finding that retarded persons should receive treatment in the "least restrictive environment" is judicially enforceable. Rather, this brief addresses an important subsidiary issue which is before the Court: assuming *arguendo* the finding is judicially enforceable, did Congress intend that it should be implemented with a presumption in favor of CLAs?

An understanding of the specialized world about which Congress was legislating "give[s] life to the dead words of a statute dealing with it" (*United States* v. *Maher*, 307 U.S. 148, 166). The court below misunderstood the nature of the population of mentally retarded persons who reside in institutions, and it misunderstood as well the relative capacities of institutions and CLAs to provide treatment to that specialized population. Its construction of the statute consequently was premised upon a series of misconceptions. We show this in Part I.

In Part II, we show from the language, structure and history of the Act, examined free of those misconceptions, that Congress did not mandate a presumption in favor of deinstitutionalization. The provision upon which the court below relied (42 U.S.C. § 6010(2)), cannot be construed to establish such a presumption; and the provision which designates the programs for which federal funds are to be utilized by the States (42 U.S.C. § 6063) shows that the presumption is in fact contrary to congressional intent.

Minnesota, Project Report No. 5, 1979); R. Edgerton, *Issues Relating to the Quality of Life Among Retarded Persons*, in THE MENTALLY RETARDED AND SOCIETY 127, 129-130 (M. Begab ed. 1975); Comptroller General of the United States, Returning the Mentally Disabled to the Community 8-25 (Report to the Congress, 1977).

The Act does not define the term "community living arrangements." Neither did the court of appeals. As the dissent noted, one of plaintiffs' experts testified at trial that rented rooms at Holiday Inns are "one type of community-living arrangement." (612 F.2d at 128, n. 5).

ARGUMENT

I. THE COURT OF APPEALS TOTALLY MISUNDERSTOOD THE NATURE OF THE DISABILITIES AND NEEDS OF THOSE RETARDED PEOPLE WHO PRESENTLY RESIDE IN INSTITUTIONS.

A. The Degree of the Disabilities Suffered by the Mentally Retarded Residents of Public Institutions Is Far More Severe Than the Court Below Believed.

The root of the lower court's error was its failure to appreciate the nature and extent of the disabilities suffered by the mentally retarded residents of institutions such as Pennhurst. Although acknowledging that "some" Pennhurst residents suffer from physical as well as mental disabilities, and that "some" cannot care for themselves, the court asserted that "[w]hile the mentally retarded do suffer educational difficulties, the level of their functioning can be improved by individualized training." 612 F.2d at 92. The court believed there is broad potential for "remediation of the delayed learning process" in mentally retarded persons, if proper treatment is provided "under normalization principles." *Id.* at 93. The district court engaged in even more heroic optimism, explaining that "[m]ental retardation is primarily an educational problem," that "with proper habilitation, the level of functioning of every retarded person may be improved," and that "[a]n individual may be functioning at a retarded level due to lack of education and/or training, and once supplied with that education and/or training, may be removed from the ranks of the retarded." Pet. App. 103a and n.5. Fortified by that rosy view, the district court agreed with "[a]ll the parties to this litigation . . . that given appropriate community facilities, all the residents at Pennhurst, even the most profoundly retarded with multiple handicaps, should be living in the community." *Id.* at 131a.[2]

[2] As explained in the Motion, pp. iv-v, because of their particular interests "the parties to this litigation" did not present a balanced view of these matters, and the Parents-Staff Association which sought to correct that imbalance was denied intervention, with the result that the trial testimony was one-sided.

The lower courts' optimism may be justified for most retarded persons—i.e., for those with relatively little retardation. But most of those people live at home with their families, or already live in CLAs.[3] Only a very small percentage of retarded persons live in institutions, but they are, by and large, the most seriously retarded, with prospects altogether different from those whose retardation is less acute.

The great majority of retarded people—some 89%—are classified as only "mildly" retarded. Of the remainder, 6% are "moderately" retarded, with an IQ between 36 and 51; 3.5% are "severely" retarded, with an IQ between 20 and 35; and 1.5% are "profoundly" retarded, with an IQ below 20.[4] But while the severely and profoundly retarded constitute only 5% of the retarded population, at Pennhurst, 74% of the residents are either severely or profoundly retarded. Pet. App. 112a. And that is typical; nationwide, 44% of the residents of public institutions for the retarded are profoundly retarded, and 30% severely retarded.[5] Hence, generalizations about "the mentally retarded"—such as the district court's assertion that "[e]ighty-five percent of the mentally retarded can be employed"[6]—are inapplicable to the residents of public institutions, a specialized population of the most difficult cases.

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[3] The retarded population numbers in the millions. See C. Overboe and Y. Wang, Behavioral and Physical Characteristics of Developmentally Disabled Individuals 9 (University of Wisconsin—Madison, Waisman Center, 1979). Of these, only some 140,000 are in institutions. R. Scheerenberger, Public Residential Services for the Mentally Retarded 3-5 (National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1979).

[4] See Pet. App. 104a; C. Overboe and Y. Wang, *supra* at 14. And for a general treatment of the nature of mental retardation, see D. Balla and E. Zigler, *Mental Retardation*, in NEW PERSPECTIVES IN ABNORMAL PSYCHOLOGY 396-416 (A. Kazdin, et al., eds., 1980).

[5] C. Overboe and Y. Wang, *supra* at 45.

[6] Pet. App. 133a.

Profoundly retarded individuals generally cannot aspire to a mental age of more than 2 to 2½ years. C. CLELAND, THE PROFOUNDLY MENTALLY RETARDED 3 (1979). "In profound retardation, there will rarely be any intelligible speech even at adulthood except for a few individuals who may say 'mama' or 'da-da.' . . . Often, sensory defects, skeletal anomalies, or other disabilities co-exist in profoundly retarded persons. . . . Therefore, total life support is essential to their survival, and up to 40% of the profoundly retarded are either bedfast or semi-ambulatory. . . ." *Id.* at 3. The average age at death is under 40. *Id.* at 8.

Some 80% of profoundly retarded persons cannot control their urination or bowel movements (*id.* at 58); highly aggressive behavior is very common (*id.* at 23-25); and such habits as pica (eating of dirt and other objects) and coprophagy (eating of feces) are "not infrequently observed." *Id.* at 52. The helplessness of these individuals has been poignantly captured by one expert in these terms:

> Left to his own resources, even in a grocery store, the profoundly retarded person dies within a matter of days of starvation if he does not meet with accidental death before that.

Bowman, Neglect of the Profoundly Retarded, letter reprinted in 11 PCMR Message 2 (1968).

The picture is not much brighter with respect to the "severely" retarded, who have a mental age generally below 3½ to 4 years, and only the bare rudiments of speech. CLELAND, *supra* at 3. And these are permanent, incurable disabilities, generally resulting from organic brain damage. See, e.g., R. ISAACSON, MEETING THE NEEDS OF THE RETARDED 79 (1977).

Moreover, in general between 65 and 100% of the residents of public institutions for the retarded have at least one major handicap in addition to their retardation, and over a third have two or more such handicaps;[7] 25% cannot

[7] C. Overboe and Y. Wang, *supra* at 42, 46, 67-68.

walk;[8] 24% have impaired use of their hands or arms;[9] 32.5% have epilepsy;[10] 9.7% are blind or deaf.[11]

The court of appeals apparently was unaware of these facts when it described retardation as merely an "educational" difficulty. And as we now show, the court's belief that virtually all the retarded people in institutions could be "normalized" in "less restrictive" settings—which underpinned its adoption of the presumption in favor of deinstitutionalization—is similarly divorced from reality.

B. The Reality of Mental Retardation Is Inconsistent with a Presumption in Favor of Deinstitutionalization.

1. It Cannot Be Assumed That For a Particular Retarded Individual, a CLA Will be "Less Restrictive" or "More Normalizing" than an Institution.

In construing the Act to create a presumption in favor of transferring retarded people from institutions to CLAs, the court of appeals emphasized the district court's "finding" that CIAs are better attuned to "normalization principals," because they are "closer to and more reflective of the normal society" than are institutions, which the court characterized as necessarily "separate" and "isolated." 612 F.2d at 93. The court also assumed that CLAs are intrinsically "less restrictive" of a person's liberty than are institutions. *Id.* at 114. These simplistic assumptions are misconceived.

a). **"Restrictiveness."** For those retarded people who could conceivably be transferred to a CLA,[12] the mere fact that a particular institution is not located "in the commu-

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[8] *Id* at 43.

[9] *Ibid.*

[10] *Id.* at 46.

[11] *Ibid.*

[12] As we show in Part B-2, *infra*, for many retarded people transfer to a CLA would be disastrous because a CLA could not provide the comprehensive care they need.

nity," or that it is "large," does not mean that the institution is necessarily more restrictive of personal liberty than a CLA would be. In the first place, the conditions which afford meaningful freedom for retarded people are different than for normal people:

> [H]ow do we determine "restrictiveness"? It may be naive to assume that the most "normative" setting is necessarily the least restrictive for everyone. What feels restrictive to one person may feel unconstraining to another. A wheelchair is a restriction to an ambulatory person, but it provides increased freedom to a paraplegic. The problem is especially complicated for persons suffering sensory or cognitive impairment. A setting which provides freedom to a nonhandicapped person may be more restrictive to a handicapped person than a specially designed prosthetic environment. And the problem is more complicated still when the least restrictive alternative test is applied to the larger social environment in which a retarded person lives as opposed to facilities designed for specific programs. A small group home nestled in a hostile neighborhood, even if honorifically labeled as "community care," or a place "in the community," may be considerably more restrictive to its residents than a small village-type facility in which retarded residents are full participants in their own "community," even if some might call that community an "institution." The ultimate complexity of the least-restrictive alternative analysis, however, may be that restrictiveness and freedom are experiences of individuals, and that categorical determinations of these matters will always be clumsy.

Roos, *The Law and Mentally Retarded People: An Uncertain Future*, 31 STAN.L.REV. 613, 622 (1979).

The court's assumption that institutions are inherently more "restrictive" than CLAs overlooks not only the need to define what is "restrictive" for the unique population involved, but also the fact that there are enormous differences in degree of restrictiveness among individual institutions, and among individuals CLAs:

> An institution of over a thousand residents can be an impersonal, overcrowded, inhuman place, but it can also

> be a happy community with the pulsing life of a prosperious village, where everybody can find what he needs. On the other hand, a small group home for six retarded persons can be a pleasant family-like place, but it can also be a ghetto, where handicapped persons live out their lives without the necessary special services and without the sympathy of their neighbors.

M. Egg-Benes, *Integration of the Mentally Retarded in Society*, in RESEARCH TO PRACTICE IN MENTAL RETARDATION, vol. 1, (hereafter RESEARCH TO PRACTICE) at 351-352 (P. Mittler ed. 1977).

Thus, contrary to the court's view of CLAs as citadels of freedom, a thorough study of CLAs in Southern California found that among the "board and care" facilities—one of the most prevalent types of CLAs—"[m]ost . . . are closed, ghetto-like places, whose residents are walled off from any access to community life." R. Edgerton, *Issues Relating to the Quality of Life Among Mentally Retarded Persons*, in THE MENTALLY RETARDED AND SOCIETY 130 (M. Begab ed. 1975). The study concluded that "[f]or most mentally retarded people in this system . . ., the little institutions where they now reside appear to be no better than the large ones from which they came, and some are manifestly worse." *Id.* at 131. Other studies have confirmed that many CLAs are simply "creating socially isolated total institutions within the community." E. Butler and A. Bjaanes, *A Typology of Community Care Facilities and Differential Normalization Outcomes*, in RESEARCH TO PRACTICE, *supra*, at 342.

Just as there is no guarantee that a CLA will provide "freedom," neither does it follow that an institution will impose unnecessary restraints. As stated by Dr. John Throne of the University of Kansas and the Lakemary Center for Exceptional Children:

> [T]here is little doubt that all, or virtually all institutions can meet many or most if not all of the myriad and diverse needs of the retarded . . . without undue or inappropriate restrictions on their freedoms. This principle has been demonstrated in practice time and time again in a variety of institutions provided with the necessary organizational, administrative, and man-

> agerial structures. Those denying in court the principle or the practice appear to be unaware of the size and significance of the literature on the subject . . . .
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> * * *
>
> [T]here are simply no preestablished grounds . . . for assuming that one category of institution, from "large" through family abode to dwelling for one . . . is inherently more or inherently less restrictive than any other . . . .
>
> Depending solely on the organizational, administrative, and managerial policies and procedures adopted, doors in any institution can be locked, closed or open. Comings and goings can be stopped, intermittent or free. Institutions can be throttling, regulating or permissive. They can defeat, bore, or enrich. They can kill. They can stultify. They can enliven.[13]

b). **"Normalization."** The considerations just discussed also reveal the fallacies in the court's assumption that CLAs inherently provide a more "normal" life than institutions, and thereby serve to "normalize" their residents.[14]

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[13] J. Throne, Is Deinstitutionalization Dictated by the Least Restrictiveness Principle? (paper presented at the Meeting of the American Association on Mental Deficiency, Miami Beach, Florida, May-June, 1979). See also R. ISAACSON, *supra* at 164. And see note 21 *infra*. Indeed, because institutions can offer expansive grounds with many opportunities for recreation and other activities, they offer a wealth of possibilities for a rich and active life, without the inhibiting dangers which the community poses to many of the retarded. See, e.g., J. Tizard, *The Role of Social Institutions in the Causation, Prevention and Alleviation of Mental Retardation*, in SOCIAL-CULTURAL ASPECTS OF MENTAL RETARDATION 281-321 (H. Haywood, ed. 1970) ("one of [the] attractions of large institutions, as communities in which to live, lies in the fact that they commonly have farms, gardens, and playgrounds attached to them").

[14] The lower court's emphasis on "normalization" raises the threshold problem that neither Congress nor the profession has defined what the objectives of an habilitation program should be. For mental retardation, unlike physical diseases and most mental illnesses, there is no such thing as a "cure," and conceptions of the appropriate purposes of habilitation are necessarily complex. One

For many retarded people, removal from an institution in no way marks the beginning of a "normal" life or of meaningful community contact. For example, some 26 percent of the retarded who have been released from public institutions were moved to nursing homes,[15] often as a di-

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possible objective, which the lower courts erroneously assumed to be the only valid objective, is "normalization"—that is, an effort to equip retarded individuals to live as "normal" a life as possible. "Under this view, the professional helping the retarded is in effect a 'human manager' inducing in the retarded person the most socially acceptable behavior possible." Roos, *supra*, 31 STAN.L. REV. at 616. But the induction of socially acceptable behavior is not considered the only proper objective of habilitation programs. Other objectives include the maximization of intellectual potential, or of independence and self-sufficiency, or of economic productivity, or simply of happiness and contentment. *Id.* at 616-617. See also M. ROSEN, et al., HABILITATION OF THE HANDICAPPED 115-125 (1977). Indeed, if pursued without consideration of such other goals, "normalization" would lead to no more than a "pretense of equality" (Schwartz, *Normalization and Idealism*, 15 MENTAL RETARDATION 39 (December 1977), at the expense of "more enduring human goals. . . ." Mesibov, *Alternatives to the Principle of Normalization*, 14 MENTAL RETARDATION 31 (October 1976). See also R. ISAACSON, *supra* at 85-86, 181; Browning, *Normalization at What Price?* 15 MENTAL RETARDATION 24 (December 1977).

It follows that the choice of the objectives for an habilitation program is "basically dependent on ethical values. . . . These goals may be mutually incompatible, and each would very likely lead to markedly different programs." P. Roos, *Evolutionary Changes of the Residential Facility*, in RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED (hereinafter RESIDENTIAL FACILITIES) 29, 55 (A. Baumeister and E. Butterfield eds., 1970). Thus, any attempt to prescribe the "best" type of habilitation program necessarily involves making choices of social policy which there is nothing to suggest Congress made in adopting the Act—choices which the court below made according to its own lights.

[15] Comptroller General, Returning the Mentally Disabled to the Community, *supra* note 1, at 11 (1977). Indeed, the number of retarded people in nursing homes increased by 48 percent between the years 1969 and 1974. *Ibid.*

rect result of litigation directed against public institutions.[16] In the typical nursing home, life for the retarded consists "[f]or the most part . . . [of] just sitting, watching television, or lying on their beds." [17]

Even in smaller CLAs, the residents generally have little contact with the community, and are not exposed to activities which might have a "normalizing" effect. See, e.g., E. Butler and A. Bjannes, *supra* at 342, 345-346;[18] R. Edgerton, *supra;* H. Gunzburg, *Editorial,* in THE BRITISH JOURNAL OF MENTAL SUBNORMALITY, vol. XXVIII, Part 2, at 63-65 (December 1972); A Birenbaum and M. Re, *Resettling Mentally Retarded Adults in the Community—Almost 4 Years Later,* 83 AMERICAN JOURNAL OF MENTAL DEFICIENCY 323, 327-329 (1970).[19]

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[16] *Id* at 13. And see p. .... *infra.*

[17] *Id.* at 14.

[18] "Our data show that small facilities rarely use outside opportunities and that wide interaction with external settings is critically absent. . . ." *Id.* at 342.

[19] Because of the special needs of the retarded, merely placing a retarded individual in a superficially normal environment is of little, if any, significance. Any meaningful efforts at "normalization" must depend on the provision of specialized services which enable a retarded person to become actively involved, to the extent possible, in normal activities. As stated by Butler and Bjannes, *supra* at 345:

> In order to provide a normalizing environment, community care facilities must provide an environment which is actively enriched both with internal programs and external contact and exchange.
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> * * * *
>
> While this is obvious in large facilities, it is *particularly critical in small care facilities,* which, by virtue of size, must include activities and external interaction to approximate a normal environment. Isolation in small care facilities results in a social setting populated only by developmentally disabled persons, thus restricting activities, the number of role models, and experiences necessary for normalization to occur (emphasis added).

Conversely, there is nothing about institutions which makes them inherently incompatible with the concept of "normal" life for the retarded. As stated by Egg-Benes, *supra*, if properly developed and managed an institution can be "a happy community with the pulsing life of a prosperous village, where everybody can find what he needs." Steps taken by one institution, serving severely and profoundly retarded people with major behavioral problems, to "provide a livable and humane situation in which these residents could live comfortably and productively" were described in K. Kreger, *Compensatory Environment Programming for the Severely Retarded Behaviorally Disturbed*, 10 MENTAL RETARDATION 29, 30 (August, 1971):

> Among the activities that were introduced were such things as developing a garden plot, raising plants in the building, playing shuffleboard and pool, setting up large rolls of paper across dayroom walls for coloring and art work, going for walks in small groups, going fishing at a nearby stream, riding bicycles, repairing furniture, polishing stones, and even such things as taking groups of residents out of doors late at night to observe the sky and to see what the world looks like to normal persons who are free and able anytime to walk out of doors and see the sky and the stars. Likewise, we have introduced boy-girl activities, dances, parties, and boys and girls going on walks together accompanied by staff.

In short, institutions can encourage and facilitate participation by retarded people in many facets of "normal life." Many institutions do; the rest could.[20] For what

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But as Butler and Bjannes found, a great many CLAs—particularly the smaller ones—do *not* provide these necessary services. *Id.* at 342-346. Indeed, Butler and Bjannes have found hat institutions are generally superior to CLAs in providing the kinds of services which enable retarded people to participate in activities of normal life. See E. Butler and A. Bjannes, Deinstitutionalization, Environmental Normalization, and Client Normalization 6-11 (paper presented at the American Association on Mental Deficiency and National Association of Private Residential Facilities for the Mentally Retarded, San Francisco, California, May 14, 1980).

[20] See, e.g. M. ROSEN, et al., *An Institution Transformed*, in

matters is not the location of a facility, but how it is managed, and what policies its staff implements.[21]

HABILITATION OF THE HANDICAPPED *supra*, at 61-74; E. Butterfield and E. Zigler, *The Influence of Differing Institutional Social Climates on the Effectiveness of Social Reinforcement in the Mentally Retarded*, in 70 AMERICAN JOURNAL OF MENTAL DEFICIENCY 48-49 (1965). In this regard it should be emphasized that the abusive conditions which the court below found to have prevailed in the past at Pennhurst represent an extreme situation which need not—and ought not—exist at any institution. It is perhaps natural that in the wake of well-publicized revelations concerning "the indignities of back ward life" in the worst institutions, to observers who are not fully informed "all institutions have been tainted and community-based services have taken on a saintly glow." M. Begab, *The Mentally Retarded and Society: Trends and Issues*, in THE MENTALLY RETARDED AND SOCIETY 18 (M. Begab ed 1975). But "[b]oth notions distort the facts." *Ibid.* Thus:

> Simple black and white generalizations cannot be drawn. Institutions are complex social environments differing in size, degree of freedom, or regimentation afforded, in quality of supervision and leadership (which itself may vary in degree of authoritarian control, punitiveness, benevolence), in physical structure, population, and characteristics of residents, and in degree of community involvement, medical versus educational or habilitation orientation, and numerous other variables.

Rosen, *supra* at 109.

[21] See, e.g., J. Throne, *Deinstitutionalization: Too Wide a Swath*, 18 MENTAL RETARDATION 171 (August, 1979); M. Begab, *supra* at 17-21; R. KING, N. RAINES AND J. TAZARD, PATTERNS OF RESIDENTIAL CARE 114-115 (1971). Institutions in no way reject the concept that those retarded people who could potentially benefit from life in the community should be enabled to do so; to the contrary, to an ever-increasing extent one of the primary objectives of institutions is to prepare residents for community life insofar as possible. And institutions can offer programs uniquely suited to that end, such as sheltered workshops, half-way houses, "quarter-way houses" (in which retarded people live in the institution but work in the community) and home-like cottages on institution grounds. See, e.g., Rosen, *supra* note 14, at 61-74; P. Roos, *Evolutionary Changes of the Residential Facility*, *supra* note 14, at 35-36; J. Parnicky, *Pathways Toward Independence for Institutionalized, Moderately Retarded Adults*, in RESEARCH TO PRACTICE, *supra* at

Of course, in many respects the life of a retarded person in an institution—or in a CLA—can never be fully normal: "[a]lthough there can be no question that retarded people can be treated more normally than in the past, at some point we must all come to grips with the fact that they are in fact different because they lack a most important asset for success in our complex, industrialized society." Mesibov, *Alternatives to the Principle of Normalization, supra* note 14, at 31. If they are to develop some of the skills and capacities of normal people which they lack, retarded individuals cannot simply be treated as if they were already normal. See, e.g., J. Throne, *Normalization Through the Normalization Principle: Right Ends, Wrong Means*, 13 MENTAL RETARDATION 23 (October, 1975); R. ISAACSON, *supra* at 16. For this reason, to the extent that a retarded person living in an institution resides in a "sheltered environment" and has more contact with other retarded people than with "the community," it is far from clear that this situation is undesirable.

295-304. Indeed, "to have a good community program you must have a good institutional program . . . ." Testimony of Dr. David Rosen, then President of the American Association on Mental Deficiency, in *Hearings on H.R. 11511, etc. before the Subcomm. on Public Health and Environment of the House Comm. on Interstate and Foreign Commerce* 1046 (93 Cong., 2d Sess. 1974). As the foregoing indicates, the court of appeals was wrong in its belief that institutions necessarily bring about "the imposition or facilitation of increased retardation." 612 F.2d at 93. In general, studies of institutions have found a positive impact on the development of self-confidence, self-direction, and motivation. See ROSEN, *supra* at 108. In addition, studies of several institutions have found general increases in IQs, although studies of some other institutions have found general decreases. See M. Begab, *supra*, at 19-20; D. Primrose, *Asylum*, in RESEARCH TO PRACTICE, *supra* at 264-265. The conclusion which is supported by the data is that institutionalization can have either a beneficial or an adverse impact on personality development and intelligence, depending on the programs of the particular institution and the needs of the particular resident. See, e.g., J. Throne, *Deinstitutionalization: Too Wide a Swath, supra*, at 174.

For example, "[o]ne advantage of a large institution is the ability to form peer groups for the patients, groups where they are no longer the least efficient member and where they are not ridiculed because of their inadequacy." D. Primrose, *Asylum, supra* note 21, at 265. See also P. Browning, *Normalization at What Price?, supra* note 14. Forcing retarded individuals to leave their peers and enter the "community" often leads to "enormous loss, isolation and self-hatred." Schwartz, *Normalization and Idealism, supra* note 14, at 39.[22] "We have failed to examine the capacity of retarded persons to adapt to the pressures of this highly industrialized and competitive society, and have in essence forced upon them defensive maneuvers that minimize emotional growth and perception of reality. . . . The personal life of the retarded person is . . . reduced to more and more frustration and isolation." *Id.* at 38-39. And see generally EDGERTON, THE CLOAK OF COMPETENCE (1967); R. ISAACSON, *supra;* H. Gunzburg, *supra,* at 64.

2. For Many Retarded People, Only an Institution Can Provide Adequate Services and Programs.

What has been said to this point is sufficient to show the incorrectness of the court's belief that CLAs are to be favored as inherently more "normal" and less "restrictive" than institutions. But that is only one dimension of the court's error. Another, equally important, lies in the fact that for a great many of the retarded—and particularly the most severe cases, who comprise such a large percentage of the population of public institutions—CLAs cannot provide the comprehensive care and programs which they need.

"[T]he marked heterogeneity of the retarded population clearly indicates that what is possible for some is not so

[22] Even apart from the loss of peers, the disruption of a retarded individual's environment which is caused by a move from an institution to a CLA in itself tends to produce severe emotional problems. See W. Cochran, P. Sran, and G. Varano, *The Relocation Syndrome in Mentally Retarded Individuals,* 15 MENTAL RETARDATION 10 (April 1977).

for others," and this "militates against any single pattern or program [of care]." Begab, *supra* note 20, at 17, 18. As has been noted (pp. 3-6 *supra*), many retarded people—particularly those with the most difficult problems, who comprise the bulk of the population of public institutions—require total care and a vast array of services. Such comprehensive services are "logistically difficult to provide in scattered facilities serving individual or small groups of [the retarded]," but can readily be made available in institutions. Id. at 18.[23]

A recent survey found that in all three areas of services reviewed—educational services, medical services, and adult programming and behavior management programs—CLAs in every region of the country are providing inadequate ser-

[23] Obviously, a CLA serving a handful of residents cannot provide the necessary services itself. Nor is it safe to rely on services in the community, because retarded people require the care of specialists. This is true not only as to those types of services which are most directly associated with the retarded (such as unique educational programs, therapy, etc.) but as to virtually *all* the services a retarded person needs. For example, even for what would ordinarily be a routine illness, a general practioner in the community is likely to experience great difficulty in attempting to treat a profoundly retarded adult with multiple disabilities who cannot describe his sypmtoms, whose behavior may be erratic, and whose disabilities are likely to be unfamiliar to the doctor. See J. Clements, *Medical Services in Institutions for the Mentally Retarded*, in RESIDENTIAL FACILITIES, *supra* at 317-318. And even were it possible to provide the necessary specialized services at sites in the community, it would be an extremely difficult matter to assure access by the residents of each of the separate CLAs to the services as needed. In contrast, an institution can provide virtually all the necessary services on its premises, and can therefore make them readily accessible to the residents. See generally RESIDENTIAL FACILITIES, supra. What is more, this accessibility makes it possible to establish programs which could not readily be established outside the institution, by "capitaliz[ing] on the inherent advantages of the institutional structure. . . ." C. Blue, *Education of the Mentally Retarded in Residential Settings*, in RESIDENTIAL FACILITIES, *supra* at 289. See also *id.* at 303-305.

vices for the severely and profoundly retarded. R. Scheerenberger, Community Programs and Services 8 (National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1980).[24]

To apply a presumption in favor of CLAs is thus rash. "Knowing the fragility of the [profoundly mentally retarded] and the hazards of relocating them . . ., deinstitutionalization zealots could be consigning them to an early death." C. Cleland, THE PROFOUNDLY MENTALLY RETARDED, *supra*, at 129.[25]

In addition to the problem of services, the behavior maladjustments of many retarded people can preclude successful placement in a CLA. See, e.g., R. Eyman and T. Call, *Maladaptive Behavior and Community Placement of Mentally Retarded Persons*, 82 AMERICAN JOURNAL OF MENTAL DEFICIENCY 137, 143 (1977).

Factors such as these no doubt explain why, in Pennsylvania, the severely or profoundly retarded constitute only 14% of the residents of CLAs, but 72% of the residents of institutions.[26] Placement in the community is simply un-

[24] Similarly, "[w]hile the quality of alternative living facilities was rated rather adequate for the more mildly affected, it was considered less than adequate for the severely and profoundly retarded." *Id.* at 30. The general failure of CLAs to provide adequate services explains why CLAs are often thought to be a less costly means of habilitation, per resident, than institutions. The most thorough study of this question concludes that if CLAs provided the same quality of services as are available in institutions, they would *not* be less costly than institutions. T. Mayeda, et al., Current Costs for Care of Developmentally Disabled Clients in Community Based and Institutional Settings 141-142 (U.C.L.A.-Neuropsychiatric Institute Research Group at Pacific State Hospital, Pomona, California, June 1977).

[25] See Miller, *Deinstitutionalization and Mortality Trends for the Profoundly Retarded*, in RESEARCH WITH THE PROFOUNDLY RETARDED, vol. 1 (C. Cleland ed. 1975).

[26] Longitudinal Study of the Court—Ordered Deinstitutionalization of Pennhurst: Historical Overview I, at 88 (Report to U.S. Department of Health and Human Services submitted by Govern-

tenable for a great many of these individuals; they are in an institution because "there is no other way to care for them." [27]

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ment Studies and Systems, Philadelphia, Pennsylvania, April 7, 1980). Also instructive in this regard is the following description of the entry requirements which ENCOR, a system of CLAs in Nebraska, established for some of its facilities:

> They included such things as: (1) must have self-help skills; (2) must be able to use public transportation; (3) must be independently employed; (4) must be capable of independent living; (5) must be able to handle money. In effect, we very neatly excluded any person who happened to be moderately, severely or profoundly retarded, or who had not yet developed one or all of those skills.

Skarnoulis, *Least Restrictive Alternatives in Residential Services,* JOURNAL OF THE AMERICAN ASSOCIATION FOR THE EDUCATION OF THE SEVERELY PROFOUNDLY HANDICAPPED, vol. 1, issue 3 (January, 1976).

[27] R. ISAACSON, *supra* at 151. See also *id.* at 15, 87; Tizard, *supra*; at 294-295. In recent years, as deinstitutionalization of the mentally retarded has increased, so has the number of readmissions to institutions, such that the "higher relase rates appear to be largely offset by soaring readmissions." J. Conroy, *Trends in Deinstitutionalization of the Mentally Retarded,* 15 MENTAL RETARDATION 46 (August 1977). According to a leading study, the "failure rate" of mentally retarded people who leave the institution (i.e., the proportion who are later readmitted) was only about 10 percent in the period 1936-1953, but it soared to nearly 50 percent in the period 1960-1970. R. McCarver and E. Craig, *Placement of the Retarded in the Community: Prognosis and Outcome,* 7 INTERNATIONAL REVIEW OF RESEARCH IN MENTAL RETARDATION 145, 180-186 (1974). Another study found that the rate of readmissions directly from CLAs to institutions more than doubled between 1977 and 1979. Scheerenberger, *supra* note 3 at 31. Although one study found a lower readmission rate, the study was limited to facilities selected from among only certain types of CLAs—excluding, for example, all nursing homes—and the facilities selected had virtually no profoundly retarded residents. E. GOLLAY, et al., COMING BACK 26 (1978).

3. A System Relying More Heavily on CLAs Would Be Unstable and Inadequately Monitored and Would Not Assure Continuity of Care.

Apart from the limitations of CLAs which have already been noted, massive transfers from public institutions to CLAs would introduce dangerous instability into the system of services for the retarded. Over 90% of CLAs are privately owned,[27a] and unlike larger state institutions, these small enterprises frequently go out of business. "Independent operators, often married couples seeking additional sources of income, offer little assurance of long-range stability. The disruptive impact to the retarded . . . of precipitate closings can be very devastating." Begab, *supra*, at 112.[28]

CLAs also are plagued with enormous staff turnover. In the five-county area served by Pennhurst, the average duration of employment of a CLA staff person is 6 months.[29] CLAs are less desirable places of employment than large institutions: they provide no privacy for staff members,[30] pay lower salaries (in the five-county area, 30% lower than institutions), and offer no career ladder.[31] New, untrained employees are continually brought in, creating "an unstable environment in the residence . . . disruptive to the expectations of the residents."[32] And as the decision below would result in increased transfers to CLAs of those retarded

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[27a] R. Bruininks, et al., *supra* note 1 at 64.

[28] Parents and advocates of retarded people who presently live in institutions are justifiably concerned that the CLAs into which many retarded people will be transferred "may not be permanent fixtures in the provider landscape and that retarded individuals will suffer from any dislocation in provider continuity." Longitudinal Study, *supra* note 26, at 87.

[29] *Id.* at 84.

[30] "Because most CLA staff live in the homes, they are constantly in contact with the residents and even though they have their own bedrooms, are unable to get away by themselves for more than short periods of time." *Id.* at 85.

[31] *Id.* at 85-86.

[32] *Id.* at 85.

people with the most severe problems—a group which CLAs have not generally accommodated in the past—the instability already present in the CLA system would almost certainly grow.[33]

Moreover, it would be extremely difficult to ensure adequate controls and accountability in a system based primarily on CLAs. Although strict monitoring of CLAs is critical,[34] in practice there is virtually no governmental supervision of CLAs. Pennsylvania has *no* regulations governing CLAs.[35] Nationwide, less than half the CLAs for the mentally retarded are subject to any licensing requirements with respect to their programs;[36] more than a quarter are not even subject to licensing requirements with respect to hygiene.[37]

Nor is this likely to change. Given the obvious difficulties of devising any adequate system for monitoring the thousands of CLAs, and the economic interests of CLA operators in avoiding such controls, a shift to CLAs simply rep-

[33] At present some sixty to seventy thousand retarded people live in CLAs nationwide. R. Bruininks, *supra* at 43. More than twice that number live in institutions. See note 3 *supra*.

[34] As noted, 90% of CLAs are privately owned. And some 38% are run for profit, according to a recent survey. Bruininks, *supra*, at 64. In his study of CLAs in Southern California, Edgerton concluded that the "primary source" of the generally poor quality of the CLAs was the "profit motive." *Issues Relating to the Quality of Life, supra*, at 131. As he observed, the interests of the management and staff of a CLA are often adverse to those of their clients. The staff may seek to create a "covert culture in which incompetence and dependence are rewarded," due to a desire to retain residents who could properly be released. *Id.* at 132. But while the management and staff seek to avoid "empty beds" (id. at 131), they may also have an interest in cutting corners on the more costly and taxing services that many retarded individuals require.

[35] Longitudinal Study, supra note 26 at 141.

[36] O'Connor, Home is a Good Place 26 (Monograph of the American Association of Mental Deficiency, No. 2, 1976).

[37] *Ibid.*

resents a means for many states to get out of the business of caring for the mentally retarded.[38]

A widespread movement to CLAs from large institutions would mean replacing state-operated facilities, which are subject to public oversight and constitutional standards, with a far-flung network of essentially private enterprises, many of them designed for profit, subject to no meaningful system of controls or accountability, nor, arguably, to constitutional obligations.

The validity of these concerns is borne out by recent history:

> When the deinstitutionalization movement began, there immediately followed the creation of large nursing homes and boarding homes in old, decaying neighborhoods where individuals were and are still isolated emotionally and socially from the community. . . . In some cases, rather than being 'dumped' in the back wards of institutions, the mentally disabled have been 'dumped' in the back alleys of communities where facilities are inadequate and services inaccessible.

Detroit Research Institute, The Illusion of Deinstitutionalization 3 (University of Denver, October 1978). See also AFSCME, Patients for Sale, *supra;* Comptroller General's Report, *supra* note 1.[38a]

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[38] For evidence that this indeed is occurring, see A. SCULL, DECARCERATION 150-151 (1977); American Federation of State, County and Municipal Employees, Patients for Sale 18-25 (Preliminary Draft, May 27, 1980).

[38a] In the end, the assumptions of the court below are perhaps most tellingly refuted in the letters of parents of Pennhurst residents filed with the courts below. One parent wrote:

> Let me first say that I cannot understand how Judge Broderick could make such a "blanket" ruling in regards to our retarded children. Each one has his special abilities and disabilities and if it were possible for them to function in the outside world, most parents would have kept them at home.
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> * * * *
>
> In 1968 Pennhurst was overcrowded and short handed and yes there were many problems. But today, Pennhurst has

II. THE WORDS, STRUCTURE AND LEGISLATIVE HISTORY OF THE STATUTE, VIEWED AGAINST THE REALITY JUST DESCRIBED, AFFORD NO SUPPORT FOR CONSTRUING THE STATUTE TO CREATE A PRESUMPTION IN FAVOR OF DEINSTITUTIONALIZATION.

The court below found the "presumption" in favor of CLAs in the words of § 6010(2) of the Act, specifically in the following "finding[] respecting the rights of persons with developmental disabilities":

> The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the development potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty.

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changed greatly. About seven years ago when the New Horizon Bldg. was built, our son was transferred there to Ward 48 and he has had good care. Here is a 29 year old child who needs 24 hr. care and protection. He does not talk, cannot dress himself and needs help at mealtime. He is not toilet trained and is on a 2 hr. schedule for bathroom needs. His mental age is about 1½ years. He does walk but due to some palsy, his gait is uneven. He is subject to petit and grande mal seizures but medication keeps his condition under control. He cannot think for or take care of himself.

In this building, there are heated swimming pools and my son is taken there and carefully guarded. He is taken on outings such as the Zoo, Seashore, Hershey Park, etc. There is also a fenced play area in the rear of the building.

He has room to walk the halls, a large playroom with T.V.-cartoon movies are shown and he has more freedom than if he were placed in a small apartment or home in our noisy, crowded crime ridden city. Most parents send their children to the country to get them away from the city and the underprivileged children are also sent to camps and yet Judge Broderick wants to send my handicapped child back to Phila.

* * * *

I know my son—a small cramped environment is not good for him. He becomes frustrated and high strung. He needs security of the attendants he has known these past years and

The court of appeals, believing from the distorted record made by the parties in the district court (see Motion, p. iv *supra*) that CLAs are always less "restrictive of . . . personal liberty" than institutions, understood these words to create a presumption in favor of placement in CLAs. But, as as we have shown (pp. 6-9 *supra*), it is simply not true, particularly for seriously retarded persons (and it is they who make up most of the population of institutions) that CLAs will necessarily be less restrictive of personal liberty; indeed, in many cases CLAs will be more restrictive, and in still others the answer will depend upon the relative quality and programs of the institution and the CLA between which the choice must be made. Nor is there reason to attribute to Congress, which has held lengthy hearings over a period of years, the misconceptions which guided the courts below.[39]

Congress did not in terms dictate a preference for CLAs; rather, it expressed a preference for "the setting" which is least restrictive of "the person's" personal liberty. These

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cannot take too much noise or confusion and he will certainly get this if he is moved to some small place in Phila. These attendants, nurses and doctors are his parents.

* * * *

Letter submitted to the court of appeals as an exhibit to the "Brief in Response to the Court's Request," dated August 15, 1979, by petitioner Pennhurst Parents-Staff Association. Numerous other letters expressing similar concerns, which were filed with the district court, were included in the Supplemental Appendix of the Pennhurst Parents-Staff Association in the court of appeals.

[39] The committees responsible for the enactment and amendment of the statute conducted several series of hearings in which a wide range of issues regarding habilitation of the mentally retarded were explored in depth. See *Hearings on S. 427 and S. 458 before the Subcomm. on the Handicapped of the Sen. Comm. in Labor and Public Welfare*, 93d Cong., 1st Sess. (1973); *Hearings on H.R. 11511 before the Subcomm. on Public Health and the Environment of the House Comm. on Interstate and Foreign Commerce*, 93d Cong., 2d Sess., pts. 1 and 2 (1974); *Hearings on H.R. 2954, etc. before the House Subcomm. on Public Health and the Environment of the House Comm. on Interstate and Foreign Commerce*, 94th

words call for examination of each person as an individual, and the selection of "the setting" which is least restrictive for that person. Assuming *arguendo* that this was meant to be a judicially enforceable command, there is no warrant for injecting a presumption which effectively predetermines the outcome.

Moreover, even the "least restrictive" language upon which the court below focused is not unqualified. It is but one of two intertwined objectives declared in the same sentence: the "treatment, services, and habilitation" for a retarded person "should be designed to maximize the development potential of the person *and* should be provided in the setting that is least restrictive of the person's personal liberty." As we have shown (pp. 9-18 *supra*), it will often be the case that CLAs are incapable of providing the treatment and services designed "to maximize the development potential of the person." In such instances, the statute does not express a preference for CLAs *even if* they are less "restrictive of . . . personal liberty." Rather, the "least restrictive" criterion is operative only in selecting from among those "settings" which are able to provide the "treatment, services, and habilitation . . . designed to maximize the development potential of the person." [39a]

Cong., 1st Sess. (1975); *Hearings on S. 3378 before the Subcomm. on the Handicapped of the Sen. Comm. on Human Resources,* 94th Cong., 1st Sess. (1975); *Hearings on S. 462 before the Subcomm. on the Handicapped of the Sen. Comm. on Human Resources,* 94th Cong., 1st Sess. (1975); *Hearings on S. 2600 before the Subcomm. on the Handicapped of the Sen. Comm. on Human Resources,* 95th Cong., 2d Sess. (1978).

[39a] In fact, § 6010 declares several other preferences in addition to the preference for treatment and services which "maximize . . . development potential" and are provided in the "least restrictive" setting, all of which may bear upon the proper placement of an individual. Treatment and services are to be "appropriate" (§ 6010(1)); the Federal Government and the States "have an obligation to assure that public funds are not provided to any institution or other residential program" for retarded people which does not meet certain requirements with respect to diet,

In sum, § 6010(2), read in light of the specialized world to which it is addressed, expresses a preference that each retarded person receive the individualized treatment best suited to his particular condition, in "the setting" best capable of providing that treatment without unnecessary obstruction of personal liberty. If courts are to implement this preference, they should do so freed of presumptions in favor of some settings over others—presumptions which there is no evidence Congress meant to create.

We have shown that a presumption favoring CLAs cannot be found in the section of the Act—§ 6010(2)—where the court below purported to find it. Other provisions of the Act corroborate that Congress did *not* intend such a presumption. There is only one provision of the Act which distinguishes between institutions and CLAs: § 6063, which sets the criteria to be met by the "State plans" that must be approved by the Secretary of Health and Human Services as a condition to a State's receipt of funds under the Act.[40] Section 6063 designates "four different areas of priority

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medical and dental services, use of physical and chemical restraints, opportunities for relatives to visit, and compliance with fire and safety standards (§ 6010(3)); and "all programs . . . should meet standards which are designed to assure the most favorable possible outcome for those served," and which comply with certain specified standards including, "in the case of residential programs serving persons in need of comprehensive health-related, habilitative, or rehabilitative services," standards which are at least equivalent to certain standards promulgated under the Medicaid program, "as appropriate when taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs," and, "in the case of other residential programs for persons with developmental disabilities," standards which assure that care is "appropriate to the needs of the persons being served," that "the persons admitted to facilities of such programs are persons whose needs can be met through services provided by such facilities," and that the facilities provide for "humane care . . ., are sanitary, and protect [the] rights" of those they serve (§ 6010(4)).

[40] See 42 U.S.C. § 6063(a). Noncompliance with these criteria subjects a State to withholding of funds. See 42 U.S.C. § 6065.

services,'' [41] and requires the State to select one, or at most two, of these areas as the focus of its expenditures of Federal funds.[42]

Of the four areas of ''priority services'' designated in the Act, the only one which focuses upon CLAs is ''alternative community living arrangement services,'' defined by the statute to mean ''such services as will assist persons with developmental disabilities in maintaining suitable residential arrangements in the community, . . . includ[ing] in-house services such as personal aides and attendants and other domestic assistance and supportive services, family support services, foster care services, group living services, respite care, and staff training, placement, and maintenance services.'' [43] Each of the other areas of ''priority services'' is concerned with the development of specific types of programs and services—''case management services,'' ''child development services,'' and ''nonvocational social-development services''[44]—which the State is free to implement exclusively in institutions if it chooses.

Thus, *under the terms of the Act, a State is free to apply all of its federal funds to improving institutions, and is under no requirement to utilize any of the funds to establish or expand CLAs.* The State must ''examin[e] . . . the need'' in the State for the four areas of priority services,[45] but only if the State *chooses* to make ''alternative community living arrangement services'' one of the areas of focus in its State plan must the State devote a portion of its federal funds to providing such services.[46] And, even if a State

[41] 42 U.S.C. § 6063(B)(4)(A)(i).

[42] 42 U.S.C. § 6063(b)(4)(A)(ii), (B)(ii)(I). See also 45 Fed. Reg. 31006, 31020-21 (1980) (proposed regulations to be codified at 45 C.F.R. §§ 1386.45-47). In years where the federal appropriation exceeds $60 million a state may, if it chooses, select as many as three priority areas for funding. 41 U.S.C. § 6063(b)(4)(B)(ii)(II); 45 Fed. Reg. 31020.

[43] 42 U.S.C. § 6001(8)(E).

[44] These terms are defined in § 6001(8)(C), (D) and (F).

[45] See 42 U.S.C. § 6063(b)(4)(A)(i).

[46] See 42 U.S.C. § 6063(b)(4)(B).

makes that choice, the funds it devotes to such services need not be used to transfer residents from institutions to CLAs; the funds can be used to improve the programs for existing residents of CLAs, or even simply to improve "family services."[47]

Thus, while Congress regarded the development and improvement of CLAs as one area which a State *could* choose to emphasize, it made funds equally available to those States which choose to use all of the funds to improve services at larger state institutions. Since these are the only provisions of the Act which speak directly to any distinction between institutions and CLAs, and since they reflect the judgment of Congress as to the habilitation programs which the States should be encouraged to pursue, the fact that these provisions do not require any deinstitutionalization whatsoever is powerful corrobative evidence that the Act is not intended to establish the presumption in favor of CLAs fashioned by the court of appeals.[48]

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[47] The definition of "alternative community living arrangement services" does not specifically refer to the transfer of residents from institutions to CLAs; rather, it refers to the provision of services which will assist retarded persons "in *maintaining* suitable residential arrangements," including such matters as "family support services" as well as services to improve existing CLAs. § 6001 (8)(E). Indeed, the funds which a State earmarks for "alternative community living arrangement services" can even be spent on improving certain programs of *institutions,* rather than CLAs. The expenditure rules in § 6063(b)(4)(B) apply to "service activities in . . . areas of services specified in the [State] plan;" and "[f]or purposes of this subparagraph, the term 'service activities' includes, with respect to an area of services . . . activities to increase the capacity of *institutions* and agencies to provide services in the area . . . ." 42 U.S.C. § 6063(b)(4)(B)(iv) (emphasis added).

[48] The provisions of § 6063 regarding planning and expenditures, adopted in 1978, replaced earlier provisions which *did* refer specifically to the transfer of certain retarded people from institutions to CLAs. The earlier provisions, adopted in the 1975 amendments to the statute, required each State to earmark a designated percentage of the funds received under the Act "for the purpose of assisting

CONCLUSION

Amici welcome, as much as any party to this case, the increased concern which has been focused in recent years on the needs of retarded people. As a result of this awakened attention, community-based services are being made

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it in developing and implementing plans designed to eliminate inappropriate placement in institutions of persons with developmental disabilities." P.L. 94-103, § 131(a)(4), 42 U.S.C. § 6062(a)(4) (1976) (repealed). Each State plan was required to include provisions "designed (A) to eliminate inappropriate placement in institutions of persons with developmental disabilities, and (B) to improve the quality of care and the state of surroundings of persons for whom institutional care is appropriate." P.L. 94-103, § 111(b)(20), 42 U.S.C. § 6063(b)(20) (1976) (repealed). And, the State plans were required to "support the establishment of community programs as alternatives to institutionalization and support such programs which are designed to provide services for the care and habilitation of persons with developmental disabilities, and which utilize, to the maximum extent feasible, the resources and personnel in related community programs to assure full coordination with such programs and to assure the provision of appropriate supplemental health, educational, or social services for persons with developmental disabilities." P.L. 94-103, § 111(b)(23), 42 U.S.C. § 6063(b)(23) (1976) (repealed).

While these provisions were designed to encourage the elimination of "inappropriate placements," they contained no presumption that any particular placement was in fact inappropriate. Nor could the requirement that the States "support the establishment of community programs as alternatives to institutionalizaion" have been read to establish such a presumption. The Conference Report on the 1975 amendments recognized that "the development of community resources to serve previously institutionalized individuals would be an appropriate purpose for which funds could be expended" (H.R. Rep. No. 94-473, 94th Cong., 1st Sess. 33 (1975); and Congress expected that the statute would "prompt some movement of patients from State institutions back into their communities." H.R. Rep. No. 94-58, 94th Cong., 1st Sess. 10 (1975). But that is a far cry from the ruling below, under which courts are to direct transfers in all but the "extreme situation."

More importantly, the court's construction must be tested by the provisions of the statute which are in effect today. See, e.g.,

available to those who can benefit from them; and equally important, institutions for the retarded, many of which had been allowed to decay to an intolerable degree, are being revitalized as "active training, educational, and socialization centers." [49]

To consign institutions to a disfavored status in the system of services for the mentally retarded, on the mistaken assumption that community living arrangements are presumptively a superior means of habilitation for those retarded people who are presently institutionalized, would be a serious mistake. As Dr. David Rosen, the President of the American Association on Mental Deficiency, advised Congress:

> [W]e must realize that some people are, in fact, best served for appropriate periods, not necessarily for life, in what we generally think of as institutions. For

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United States v. *Alabama*, 362 U.S. 602, 604; *Hines* v. *Davidowitz*, 312 U.S. 52, 60; *Carpenter* v. *Wabash Ry. Co.*, 309 U.S. 23, 26-27; *American Foundries* v. *Tri-City Council*, 257 U.S. 184, 201. The provisions of the current Act do not contain any reference to "inappropriate placements" or to "the establishment of community programs as alternatives to institutionalization." The sections of the 1975 amendments which did so have been replaced by the statutory scheme discussed in the text. Thus, to the extent that the 1975 amendments could have been read to provide any support for the holding of the court below, the fact that Congress *eliminated* the relevant provisions of those amendments in 1978 only reinforces the conclusion that the decision of the court of appeals is unsupportable as a construction of the statute on the books today.

[49] P. Roos, *Evolutionary Changes of the Residential Facility*, *supra* note 14, at 36. For other discussions of the prospects for improvement of institutions, see M. Rosen, et al., *An Institution Transformed*, in HABILITATION OF THE HANDICAPPED, *supra* at 61-74; J. Clements, *Planning a Residential Facility for the Mentally Retarded*, in RESIDENTIAL FACILITIES, *supra* note 14 at 59-116; C. Blue, *Education of the Mentally Retarded in Residential Settings*, *supra* note 23 at 272, 276-277; K. Kreger, *Compensatory Environment Programming for the Severely Retarded Behaviorally Disturbed*, *supra*. And see pp. 20, 21, *supra*.

these people, we need to be assured that effective current programs are continued and that new and better ones are developed.[50]

The decision below, insofar as it establishes a presumption in favor of court-ordered deinstitutionalization, should be reversed.

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[50] *Hearings on H.R. 11511, etc. before the Subcomm. on Public Health and Environment of the House Comm. on Interstate and Foreign Commerce* 1046 (93d Cong., 2d Sess. 1974).